



**FIVE-YEAR STRATEGIC PLAN ON MINORITY
HEALTH DISPARITIES**

TABLE OF CONTENTS

	Page No.
NINDS MISSION/VISION STATEMENT	4
OVERVIEW OF THE NINDS STRATEGY FOR ADDRESSING HEALTH DISPARITIES	4
NINDS AREA OF EPHASIS	5
Area of Focus I: Stroke (brain attack)	5
Area of Focus II: HIV-Associated Neurological Disease	5
Area of Focus III: Neurological Complications of Diabetes	6
Area of Focus IV: Health Disparities in Treatment and Management of Chronic Pain Disorders	6
Area of Focus V: Health Disparities in Cognitive and Emotional Health of Children	6
Area of Focus VI: Epilepsy and Status Epilepticus	7
Area of Focus VII: Injury to the Developing Brain	8
Area of Focus VIII: Research Capacity Building and Enhanced Training among Institutions and Researchers	8
Area of Focus IX: Dissemination of Public Information Outreach	8
Area of Focus X: Inclusion Policies/Activities for Minorities in Clinical Research	8
Public Comment in the Development of the Health Disparities Plan	9
Health Disparities Action Plan: Current/Future Programs and Measures	9
STROKE (BRAIN ATTACK)	9
Current Programs	9
Proposed New Directions in Stroke	10
HIV- ASSOCIATED NEUROLOGICAL DISEASE	13
Current Programs	13
Proposed New Directions in HIV-Associated Neurological Disease	13
NEUROLOGICAL COMPLICATIONS OF DIABETES	15
Current Programs	15
Proposed New Directions in Neurological Complications of Diabetes	15
HEALTH DISPARITIES IN TREATMENT AND MANAGEMENT OF CRHONIC PAIN DISORDERS	17
Current Programs	17
Proposed New Directions in Treatment and Management of Chronic Pain	17
HEALTH DISPARITIES IN COGNITIVE AND EMOTIONAL HEALTH OF CHILDREN	18
Current Programs	18
Proposed New Directions in Cognitive and Emotional Health of Children	18
EPILEPSY AND STATUS EPILEPTICUS	19
Current Programs	19
Proposed New Directions in Epilepsy and Status Epilepticus	20

TABLE OF CONTENTS (Continued)

	PAGE NO.
INJURY TO THE DEVELOPING BRAIN	21
Current Programs	21
Proposed New Directions in Injury to the Developing Brain	22
RESEARCH CAPACITY BUILDING AND ENHANCED TRAINING AMONG MINORITY INSTITUTIONS AND RESEARCHERS	22
Current Programs	22
Proposed New Directions in Research Capacity Building and Enhanced Training Among Minority Institutions and Researchers	24
DISSEMINATION OF PUBLIC INFORMATION/OUTREACH	26
Current Programs	26
Proposed New Directions in Dissemination of Public Information/Outreach	26
INCLUSION POLICIES/ACTIVITIES FOR MINORITIES IN CLINICAL RESEARCH	28
Current Programs	28
Proposed New Directions in Inclusion Policies/Activities for Minorities in Clinical Research	29
PERFORMANCE AND OUTCOME MEASURES	29
TIMEFRAME FOR PLAN IMPLEMENTATION	30

NINDS MISSION/VISION STATEMENT

The mission of the NINDS is to reduce the burden of neurological disease - a burden borne by every segment of society, by people all over the world. To this end, the Institute supports and conducts research on the healthy and diseased brain, spinal cord, and peripheral nerves.

OVERVIEW OF THE NINDS STRATEGY FOR ADDRESSING HEALTH DISPARITIES

The National Institute of Neurological Disorders and Stroke (NINDS) is the lead agency for basic and clinical research focused on the brain, spinal cord, and peripheral nerves; their development, degeneration, and regeneration; and their disorders and diseases. The NINDS has scientific interests in neurological disorders as diverse as stroke, epilepsy, multiple sclerosis, head and spinal cord injuries, Alzheimer's disease and other dementias, Parkinson's disease, neurofibromatosis, muscular dystrophy, neuroAIDS, amyotrophic lateral sclerosis, and Huntington disease. Many neurological and neuromuscular disorders are chronic disorders, characterized by progressive decline in cognitive, sensory, or motor function over a long period, resulting in disability, suffering and long-term care at tremendous cost to the patient, family, and society.

The NINDS has initiated a comprehensive health disparities planning process to define research priorities and approaches for reducing the burden of neurological disease in minority populations. We will achieve reductions in minority health disparities through consultation with the extramural neuroscience community and other Federal agencies to support targeted investments in research infrastructure and funding of ten primary areas of focus. These areas include stroke, the neurological complications of HIV/AIDS, neurological complications of diabetes, treatment and management of pain, the cognitive and emotional health in children, epilepsy, injury to the developing brain, expanding research capacity and training among minority institutions and researchers, improving access to and dissemination of research information to the public, and promoting adherence to inclusion policies for minority participation in clinical research.

The NINDS has developed collaborative partnerships and networks throughout the nation and world to investigate health problems and conduct research on neurological diseases and disorders. Our planning process will identify the most effective approaches to enhance resource sharing and collaboration between researchers at minority institutions, Federal and non-Federal research institutions, and minority communities. We will identify innovative strategies to strengthen the inclusion of minorities in clinical studies. We will develop more effective methods to promote culturally appropriate prevention, treatment and other intervention studies in under-served minority populations. We will provide leadership and training to attract and retain investigators committed to research on health disparities. Finally, we will develop strategies for educational outreach to foster improved dissemination of research-based information to minority communities.

NINDS AREAS OF EMPHASIS

The NINDS Five-year Strategic Plan on Minority Health Disparities will focus on ten areas of research of which seven are condition specific and three are general, cross-cutting the specific conditions. The condition specific areas are:

- Area of Focus I: Stroke (brain attack)
- Area of Focus II: HIV Associated Neurological Diseases
- Area of Focus III: Neurological Complications of Diabetes
- Area of Focus IV: Health Disparities in Treatment and Management of Chronic Pain Disorders
- Area of Focus V: Health Disparities in Cognitive and Emotional Health of Children
- Area of Focus VI: Epilepsy and Status Epilepticus
- Area of Focus VII: Injury to the Developing Brain

The general, cross-cutting areas are:

- Area of Focus VIII: Research Capacity Building and Enhanced Training among Minority Institutions and Researchers
- Area of Focus IX: Dissemination of Public Information/Outreach
- Area of Focus X: Inclusion Policies/Activities for Minorities in Clinical Research.

AREA OF FOCUS I: Stroke (brain attack)

Stroke is the third leading cause of death in the United States, killing approximately 150,000 Americans every year. Over 700,000 new or recurrent strokes occur each year, leaving approximately 4 million Americans living with neurological deficits due to stroke. The risk for suffering a stroke and the associated mortality increase with age, thus the frequency of stroke is expected to increase substantially with the aging of the American population.

The risk for stroke also varies among ethnic groups. The incidence of stroke is disproportionately high in the African American population, occurs at younger ages, and the mortality rate is nearly 80% greater than in Caucasians. In Hispanic Americans, the incidence of subarachnoid hemorrhage is approximately two and a half times that of Caucasian Americans, and the death rate is significantly higher at younger ages. Finally, ethnic and racial minorities are the fastest growing segments of the population in several of the largest states; by the year 2020, it is anticipated that minorities will outnumber Caucasian Americans in those states.

AREA OF FOCUS II: HIV Associated Neurological Disease

HIV infection/AIDS is a leading cause of death for young adults, and approximately 375,000 have died from the disease in the United States. It is estimated that 650,000 to 900,000 Americans are infected with HIV, 15% - 30% of whom will develop some type of neurological disorder in the course of their illness.

AIDS affects minorities disproportionately. Although minorities constitute approximately 30% of the total population, they account for nearly 70% of all AIDS cases. While the number of new

(incident) cases is decreasing in some populations, it is increasing among African Americans, especially homosexual men. Of reported cases in women and children, more than 75% are minorities. Despite the reality of these data, the natural history of this infection in minorities has not been established. For example, the interaction between co-morbid conditions/pre-existing ones and HIV infection has not been documented although it is well known that minorities tend to have been exposed to or carry a higher number of infectious agents when compared to Caucasians. This knowledge has immediate and direct repercussions in the diagnosis, prognosis, and treatment of minority patients infected with HIV.

AREA OF FOCUS III: Neurological Complications of Diabetes

Diabetes is the seventh leading cause of death in the United States, affecting nearly 16 million Americans. Compared to Caucasians, the prevalence of diabetes in Hispanic Americans and in African Americans is approximately 50% and 70% higher, respectively. Among Native Americans and Alaskan Natives, the prevalence of diabetes is more than twice that of Caucasian Americans, being the highest in the world among the Pima tribe. Thus, the burden of diabetic complications, including sensori-motor peripheral neuropathy is disproportional in minority populations. Also, there is evidence that lower extremity amputations, which to some extent reflect neuropathology, occur more frequently among diabetics who are minorities.

AREA OF FOCUS IV: Health Disparities in Treatment and Management of Chronic Pain Disorders

Chronic pain disorders, such as migraine headaches, may be more prevalent in minority populations, or present special problems when considering therapeutic approaches. Further, recent studies indicate inadequate treatment for pain in minority populations, and ethnic differences in the perception of pain. In order to stimulate research, NINDS as a lead Institute for the Pain Research Consortium at NIH, will direct research efforts to identify treatment and management strategies for chronic pain conditions in diverse populations. This initiative is of particular interest to NINDS, and potentially to members of the NIH Pain Research Consortium, the NIH Intramural community, as well as to potential partners in pharmaceutical and biotechnology industries.

AREA OF FOCUS V: Health Disparities in Cognitive and Emotional Health of Children

Minority children in urban centers are at increased risk for adverse health outcomes due to chronic exposure to negative environmental factors including toxic substances, violent neighborhoods, and impoverished educational facilities. A large percentage of these children have had documented exposures to toxins (e.g., lead), and yet they have not received adequate follow-up care despite well-known impairments linked to such exposures.

In urban minority children, there is an issue of added vulnerability: it is well documented that a large percentage of minority mothers, especially African American women, give birth to low and very low birth weight babies, often associated with premature labor. As mentioned in potential Area of Focus VII, these conditions are often associated with injury to the developing brain, which will likely be compounded by the insult of environmental toxins.

Neglect, domestic and community violence are also important factors challenging the normal cognitive and emotional development of urban minority children. Symptoms of anxiety and stress similar to those associated with Post Traumatic Stress Disorder have been diagnosed with increasing frequency in these children.

AREA OF FOCUS VI: Epilepsy and Status Epilepticus

Epilepsy is characterized by recurrent unprovoked seizures. According to studies in New York, the incidence of epilepsy in the African American community in Harlem is 50% higher than in the Caucasian populations. Reasons for this disparity have been attributed to socioeconomic differences and other factors including nutrition, exposure to violence, reduced health infrastructure, and altered access to medical care. However, at an HMO in Houston, incident cases of epilepsy seemed higher in Hispanic and African American children. Recruitment from the same HMO would appear to control for access to care and socioeconomic status. Similarly, in Atlanta, African American children have a higher lifetime prevalence compared to Caucasian children under the age of 10. The lifetime prevalence in these studies is probably closest to demonstrating real differences in incidence. In the elderly, the incidence of all seizures by age 70 was about 25% in the African American community of Harlem compared to 10% in Caucasians. Age specific mortality attributable to seizures/epilepsy and overall mortality is also considerably higher in African American than in Caucasian populations. The potential roles of genetics or specific gene-environment interactions in the incidence of epilepsy have not been determined.

Status epilepticus, a serious condition characterized by acute continuous or repetitive seizures, is a major medical and neurological emergency in the United States, killing more than 50,000 Americans each year. Approximately 260,000 new or recurrent cases of status epilepticus occur each year, and approximately 8 percent of patients in coma manifest non-convulsive status epilepticus. The elderly have the highest incidence of status epilepticus, which is also associated with increased mortality. Thus, the frequency of status epilepticus and its mortality is expected to increase significantly with the aging of the American population.

The incidence of status epilepticus is disproportionately higher in African Americans across the entire age spectrum. In the elderly, it is more than four times the incidence of the general population. Moreover, recent findings suggest that there is a significantly higher genetic predisposition for African Americans to develop status epilepticus in comparison to non-minority populations.

AREA OF FOCUS VII: Injury to the Developing Brain

Injury to the pre- and postnatal brain is a leading cause of death and morbidity in children, especially injury induced by adverse fetal/perinatal environments and trauma. In the Child Health USA 1999 publication, the Department of Health and Human Services Health Resources and Services Administration (HRSA) reported that infant mortality rate, low birth weight, and very low birth weight infants (VLBW) rates are twice as high in African American infants as that of Caucasian infants. These VLBW infants are at the highest risk for physical developmental disabilities (learning and behavioral problems, motor disabilities-cerebral palsy, mental retardation) and death. In addition, certain types of traumatic injury in infancy appear to be higher in minority populations. However, the information available is insufficient to adequately identify the causes of these injuries and the subpopulations of infants at greatest risk of sustaining these injuries.

AREA OF FOCUS VIII: Research Capacity Building and Enhanced Training among Institutions and Researchers

The NINDS will continue its strategic plans to promote racial and ethnic diversity in the scientific and technology workforce. To foster an improved health status and reduce the burden of neurological disease experienced by minority Americans, the NINDS will provide programmatic assistance to minority researchers and institutions to develop and sustain basic, translational, and clinical neuroscience research programs. Support for these initiatives is recognition of the contributions this segment of the extramural community has made to advancing scientific understanding, educating and preparing minority research and health professionals, and delivering research benefits to underserved communities.

AREA OF FOCUS IX: Dissemination of Public Information Outreach

NINDS outreach activities will focus on the dissemination of up-to-date health and research-related information to minority communities and to health professionals and organizations. The information provided is broad ranging including printed and electronic materials and brochures, professional exhibits at scientific meetings, conferences and workshops and other direct communications with the extramural and intramural community.

AREA OF FOCUS X: Inclusion Policies/Activities for Minorities in Clinical Research

The NINDS has had excellent success in its compliance with NIH policies to include women and minorities in clinical research. Enrollment data and tracking of minorities and their subpopulations are updated annually.

Public Comment in the Development of the Health Disparities Plan

The NINDS 5-year Strategic Plan on Minority Health Disparities was developed in consultation and collaboration with intramural and extramural researchers (minority and majority), advocacy groups, scientific societies and other organizations. The advice and guidance received from the extramural neuroscience community identified 10 areas of research focus. A working draft of the strategic plan was published for 60 days on the NINDS Website and mailed to a variety of interests groups and voluntary organizations for public comment. The final draft was presented to the National Advisory Neurological Disorders and Stroke Council and submitted to the Trans-NIH Group on Implementation of Minority Health Disparities.

HEALTH DISPARITIES ACTION PLAN: Current/Future Programs and Measures

Our health disparities planning activities are underway and will establish the research priorities, objectives and strategies we will employ to reduce the burden of neurological disease in minority populations. An important first step to achieving our research objectives involves recruiting additional professional staff to accommodate the logistics, planning and implementation of the health disparities plan. The NINDS will complete the recruitment and hiring of two Extramural Scientist Administrators in the next few weeks. Our planning process will then consider the following proposed goals and action plans over the next several years:

AREA OF FOCUS I: Stroke (brain attack)

Current Programs

The NINDS is supporting studies on the epidemiology, etiology, pathophysiology, and secondary prevention of stroke in minority populations.

Prevention/Primary Intervention:

- *Stroke Surveillance in a Biethnic Community in southern Texas*
- *Stroke Incidence and Risks Factors in a Tri-Ethnic Region during a four-year period in northern Manhattan.*
- *Arch Plaques and Stroke in an Ethnically Mixed Community in northern Manhattan.*
- *Hemorrhagic and Ischemic Stroke among Blacks and Whites in a metropolitan population.*
- *MRFASS: Minorities, Risk Factor and Stroke Study.*
- *Recurrent Stroke Risk in Minorities*
- *Echocardiographic Stroke Predictors in a Tri-Ethnic Community*
- *Stroke M.I. and Antiphospholipid Antibodies*
- *Etiology of Geographic and Racial Differences in Stroke*
- *Warfarin vs. Aspirin in Reduced Ejection Fraction-CLIN*
- *Warfarin vs. Aspirin in Reduced Ejection Fraction-STAT*

Secondary/Tertiary Intervention:

- *Acute Brain Attack Research Program was recently established by Intramural NINDS at Suburban Hospital. Using imaging as a primary research tool, and testing therapeutic interventions, the program includes a NINDS 24-hour stroke team providing state-of-the-art, comprehensive care to stroke patients. The program has been announced in local ABC Radio affiliates, one of them (WJZW-FM) with substantial urban African American listeners.*
- *Secondary Prevention in Small Subcortical Strokes is a small pilot trial on subcortical strokes, also known as lacunar infarcts, in Mexican-American subjects.*
- *African-American Antiplatelet Stroke Prevention Study also includes significant community outreach and education activities.*

Proposed New Directions in Stroke:

Goal 1: To establish the magnitude of the disparity and the nature of the contributing factors.

(a) Workshop On Pediatric Stroke: Development of Strategies for Prevention. (Held in September 2000).

This workshop convened experts in pediatric stroke and sickle cell anemia to review current knowledge and propose strategies to address this significant health disparity in minority children. Conference participants discussed means to stimulate research using genetic approaches to extend our knowledge of stroke, including the development of projects and infrastructure to support them. The interaction between genes and environmental risk factors was emphasized as well as the role of this interaction in minority populations.

(b) Workshop on Racial/Ethnic Disparities in Stroke.

This workshop will convene experts in stroke, epidemiology, and health disparities research to focus on the definition of race, review current knowledge and the nature of contributing factors (especially for stroke in young individuals), and propose strategies for addressing health disparities and evaluation of outcomes. Topics may include:

- *Disparities in Stroke: the Full Circle.* Research on health disparities has been largely based on studies comparing outcomes between different racial/ethnic groups in the United States. Differential outcomes have been explained by several factors with race/genetics being the ultimate justification for most unexplained results. However, race/genetics has been traditionally confounded by environmental factors, including socio-economic status, lifestyle patterns, and cultural practices. International comparisons will be powerful tools to isolate the effect of race/genetics vs. other factors. We will encourage researchers to explore the causes of health disparities in racial/ethnic minorities by analyzing the effects of genetics, environment, and their interactions in stroke outcomes.

- The NINDS will support an analysis of existing data (federal, state, academic, and private sources) on the frequency of stroke in the United States and its territories, stratified by race and/or ethnicity with simultaneous assessment of the strength of the data. We propose to estimate the magnitude of the disparity and to identify critical gaps in current knowledge.

(c) Stroke Registry for Native Alaskans.

In partnership with the Alaskan Indian Health Service, the NINDS will support a stroke registry for Native Alaskans. The registry will allow trend determination of incidence, prevalence, distribution, and risk factors pertinent to this population. If successful, this initiative could be replicated into a National Stroke Registry Network, possibly including some current extramural research projects. Data from the network will be generalizable to United States population as a whole.

This goal involves three activities:

- Workshop on pediatric stroke,*
- Workshop on racial/ethnic disparities in stroke, and*
- A stroke registry for Native Alaskans.*

For the first two activities, the near-term performance measures include listings of research priorities, and program announcements (PAs) and requests for applications (RFAs) targeted to the prioritized areas. The longer-term measures include number of submitted high-quality applications in the targeted areas, number of funded applications, and number products from funded projects (e.g., publications, model intervention).

For the third activity, the near-term performance measure is a funded application to establish the registry. Longer-term performance measures include development of a model registry, funded application for a national registry, and number of submitted and funded applications that use data from either the model registry or, ultimately, a national registry.

Goal 2: To develop, pilot and evaluate culturally appropriate prevention-interventions in minority communities.

(a) Stroke and Cerebrovascular Disease Prevention-Intervention Research Program.

The NINDS, in collaboration with NHLBI and NCRR, will assist in the development of an "exploratory" Stroke and Cerebrovascular Disease Prevention/Intervention Research Program to augment and strengthen the research capabilities to reduce the burden of stroke in populations historically at increased risk from this disease. The primary goals of the Stroke and Cerebrovascular Disease Prevention/Intervention Research Program are: (1) to develop sustainable, replicable, and culturally appropriate prevention and/or intervention research programs targeted to minority populations designed to decrease the incidence and prevalence of stroke; (2) to strengthen basic, clinical and translational research capacity at minority medical schools committed to addressing health disparities related to stroke; (3) to enhance opportunities

for multidisciplinary research collaborations between minority institutions and institutions with established programs in stroke research; and (4) to increase the role of research in maintaining a vigorous and stimulating academic milieu that will inspire students and fellows to pursue careers in stroke research and other vascular diseases.

The NINDS will develop and pilot similar programs throughout the extramural community in areas of research priority specified in our health disparities strategic plan.

The primary activity of this goal is:

- *Model Stroke and Cerebrovascular Disease Prevention/Intervention Research Program.*

Near-term performance measures include submission and funding of an application for a program. Longer-term performance measures include establishment of the infrastructure for a program, establishment of the key collaborations with established external programs in stroke, submission and funding of high-quality applications for program-based research projects, and number of minority fellows or students involved in Center activities.

Goal 3: To enhance acute stroke research and care in centers serving predominantly minority populations.

(a) Acute Brain Attack Research Program in the Baltimore-Washington Area.

The NINDS will explore the feasibility of replicating its research-care program at Suburban Hospital in other medical facilities throughout the Baltimore-Washington metropolitan area targeting those serving predominantly minority populations.

The primary activity of this goal is:

- *Acute Brain Attack Research Program in the Baltimore-Washington Area.*

Near-term measures of impact will be improved stroke patient outcomes such as survivorship and physical functioning. Longer-term measures will be contingent upon project productivity and feasibility of project replication. For example, if the project is proven to be effective, a longer-term performance measure will be the number of similar centers that are established.

Goal 4: To further disseminate information on stroke, including preventive measures, warning signs, and the urgency of immediate care to minority populations.

To develop a public education campaign, the NINDS has engaged a top public relations consultant with extensive experience in developing strategic health communications for diverse audiences.

The key activity of this goal is:

- *National Public Education Campaign on Stroke.*

Near-term performance measures include development of a plan for a national, culturally appropriate communication program on stroke, development of program materials, number of communities reached.

AREA OF FOCUS II: HIV-Associated Neurological Disease

Current Programs

The NINDS is supporting studies to include multiple clinical trials to develop effective HIV treatments and to monitor gender differences in CNS infection.

Prevention/Primary Intervention:

- *Specialized Neuroscience Research Program (SNRP) on HIV and the Nervous System at the University of Puerto Rico will establish a cohort of Hispanic women, children and men with detailed neurological, neurophysiological, virological and immunological parameters to determine the major host and viral factors responsible for disease pathogenesis. The approach may lead to the development of new models of intervention in this population.*
- *Specialized Neuroscience Research Program (SNRP) on HIV and the Nervous System at the University of Hawaii will undertake a study in Hawaii on the prevalence and incidence of dementia in HIV seropositive individuals 50 years of age or more compared with younger HIV seropositive individuals. Other projects within this program will examine the role of macrophage in AIDS dementia.*

Secondary and Tertiary Intervention:

- *Neurological AIDS Research Consortium (NARC) supports investigations and treatments of the HIV infection on the nervous system utilizing the patients collected under the AIDS Clinical Trial Groups (ACTGs). Treatment of AIDS Vacuolar Myelopathy with Methionine is a randomized, double blind clinical trial.*
- *Persistence of T. pallidum in HIV CNS Infection will determine how T. pallidum infection persists after neurosyphilis therapy in HIV infected and non-infected individuals.*

Proposed New Directions in HIV-Associated Neurological Disease:

Goal 1: To understand the natural history of the development of neurological complications in minority populations, including children, and to identify effective new treatments.

(a) Analysis of Existing AIDS Data Toward Neurological Endpoints.

Extensive cohorts of AIDS and HIV infected patients exist and are well characterized in the scientific literature. The NINDS will support the analysis of existing data sets to further elucidate the nature of predictors of neurological disease, prognostic factors, and optimum timing for treatment to prevent them. Analysis will be focused on HIV-associated neuropathy and AIDS-associated dementia.

(b) Minority Cohorts in Established HIV/AIDS Protocols.

Longitudinal studies of HIV infection with established protocols exist, and the NINDS will support their expansion to include minority individuals and neurological endpoints. These protocols will be encouraged to use innovative methods to recruit and retain research participants, including the provision of minimum health care, and to add minority researchers and care providers to their working teams.

The primary activity of this goal is:

- *Development of Neuropsychological Norms for Minority Populations.*

The near-term performance measures for these activities include development and release of PAs/RFAs for targeted areas. Longer-term measures include number of submitted high-quality applications in these targeted areas, number of applications funded, and number of products from the funded projects (e.g., publications).

(c) International Collaboration on the Neurological Consequences of HIV-1 infection.

Some European centers were first to organize their research and care in response to the AIDS epidemic. These centers serve large populations from developing countries, including Western and Central Africa, India, and Latin America reflecting the ethnic/racial diversity in the United States. These populations tend to be stable and loyal to the care centers due to the universal health insurance system in most of Europe. An international research effort will bring to the NIH these unique patient populations fully characterized clinically, neuro-psychologically, and in their response to some treatment protocols. These populations will allow evaluations on new drug treatment for NeuroAIDS, which is difficult to do in the United States due to the mobility of patients (losses to follow up) and incomplete records. Also, specific questions on the neurotoxicity of viral isolates found in these populations, their viral latency in the CNS, and response to treatment can be best addressed in such collaboration between the Intramural NIH and these European centers.

This goal has three activities:

- *Analysis of Existing AIDS Data Toward Neurological Endpoints.*
- *Minority Cohorts in Established HIV/AIDS Protocols. International*
- *Collaboration on the Neurological Consequences of HIV-1 infection.*

Near-term performance measures for these activities include development and release of PAs/RFAs for targeted areas. Longer-term measures include number of submitted high-quality

applications in these targeted areas, number of applications funded, and number of products from the funded projects (e.g., publications).

Goal 2: To develop neuropsychological norms for minority populations.

(a) Neuropsychological Norms for Minority Populations.

Neuropsychological testing has been developed with little or no participation of minority populations, and norms established for the Western world have been used without adjustments to racial/ethnic minorities. These tests serve as a measure of HIV neurological involvement and are used to monitor NeuroAIDS treatment success. The fairness of using such instruments with minorities has been questioned, and their accuracy in measuring mild cognitive impairment in these populations is controversial. The NINDS will encourage the development of culturally sensitive neuropsychological instruments and/or normative data in defined racial/ethnic communities or neighborhoods with representative minority populations (catchment areas).

AREA OF FOCUS III: Neurological Complications of Diabetes

Current Programs

Current Institute Activities Related to Minority Health Disparities includes a clinical-epidemiological study of the disorder in a Native American population. This is the first study of its kind.

- *Diabetic Neuropathy Study including a large Native American population in northern Minnesota.*

Proposed New Directions in Neurological Complications of Diabetes:

Goal 1: To establish the magnitude of the disparity and the nature of the contributing factors and outcomes.

(a) Race/Ethnic Disparities in the Incidence of Diabetes Complications.

The NINDS will continue to co-fund research programs with NIDDK that are focused on sensori-motor neuropathy, its frequency, natural history, and outcomes (lower extremity amputation).

- (b) Diabetic Neuropathy on the National Health and Nutrition Examination Survey.

The on-going National Health and Nutrition Examination Survey (NHANES), National Center for Health Statistics (NCHS), recently began using a simple measure of neuropathy (monofilament), and is enrolling 5000 new cases per year. These cross-sectional evaluations are uniquely suited for studying major outcomes related to neuropathy (ulcer, amputation, mortality). In three or four years that sample (15,000 - 20,000) will be large enough to generate normative data by age, race, and sex.

Thus, the NINDS could use an inter-agency agreement to collaborate with the NCHS to include more precise measures of neuropathy to be used in the examination protocol.

(c) Analysis of Existing Diabetic Studies Toward Neurological Endpoints.

Extensive cohorts of diabetic patients exist and are well characterized in the scientific literature. The NINDS will support the analysis of existing data sets to further elucidate the frequency of sensori-motor neuropathy, the nature of its predictors, prognostic factors, and interventions to prevent or delay the development of neuropathy.

(d) Minority Cohorts in Established Diabetes Protocols.

Longitudinal studies of diabetes are currently underway, some with substantial minority representation. The NINDS will encourage these protocols to use innovative methods to recruit and retain research participants, to differentiate the types of neuropathy occurring with diabetes, to monitor the progression of disease, and to define outcomes of the neuropathy itself.

(e) Specialized Center Grant Cooperative Agreement Programs on the Neurological Complications of Diabetes in Minorities.

The NINDS will support Specialized Center Grant Cooperative Agreement programs at minority institutions to study neurological complications of diabetes in local populations and to strengthen the research capacity in those institutions.

Five activities are associated with this goal:

- *Race/Ethnic Disparities in the Incidence of Diabetes Complications.*
- *Diabetic Neuropathy on the National Health and Nutrition Examination Survey.*
- *Analysis of Existing Diabetic Studies Toward Neurological Endpoints.*
- *Minority Cohorts in Established Diabetes Protocols.*
- *Specialized Center Grant Cooperative Agreement Programs on the Neurological Complications of Diabetes in Minorities.*

Near-term performance measures for these activities include those indicating establishment of the necessary structure, for example, development and release of PAs/RFAs in the target areas. Longer-term measures include number of high-quality applications submitted on the targeted areas and number of those applications funded.

AREA OF FOCUS IV: Health Disparities in Treatment and Management of Chronic Pain Disorders

Current Programs

- *The NINDS is in the early stages of planning a major initiative on "New Directions in Pain Research II: Social, Behavioral and Clinical Issues."*

Proposed New Directions in Treatment and Management of Chronic Pain Disorders:

Goal 1: To develop treatment and management strategies for chronic pain in diverse populations.

(a) The NINDS supported a symposium for experts in pain and non-pain scientific domains, to foster collaborative partnerships and foster research to advance novel approaches to treatment and management of pain in minority populations.

(b) The NINDS will focus on studies to identify and assess barriers influencing effective chronic pain management and treatment in minority populations.

In this effort, we will determine the nature and extent of disparities in the delivery of pain treatment in target populations.

(c) The NINDS will focus on studies to identify racial/ethnic differences in pain perception and processing by addressing the incidence, severity, and consequences of pain in the general population, and in specific disease states.

(d) The NINDS will focus on studies to identify new diagnostic tools for different pain mechanisms, and objective measures of analgesic drug action. Key elements in this effort will be research to understand differences in response to analgesic drugs in diverse populations; encourage development of a quantitative sensory testing battery for pain patients; and imaging markers of analgesia and analgesic mechanisms.

Activities associated with this goal focus on research that will:

- *Determine the nature and extent of disparities in the delivery of pain treatment in target populations.*
- *Identify and assess barriers influencing effective chronic pain management and treatment in minority populations.*
- *Identify racial/ethnic differences in pain perception and processing by addressing the incidence, severity, and consequences of pain in the general population, and in specific disease states.*
- *Identify new diagnostic tools for different pain mechanisms, and objective measures of analgesic drug action through research to understand differences in response to analgesic drugs in diverse populations, and development of a quantitative sensory testing battery for pain patients; and imaging markers of analgesia and analgesic mechanisms.*

Near-term performance measures for these activities include those indicating establishment of the necessary structure, for example, development and release of PAs/RFAs in the target areas. Longer-term measures include number of high-quality applications submitted on the targeted areas and number of those applications funded.

AREA OF FOCUS V: Health Disparities in Cognitive and Emotional Health of Children

Current Programs

- *The NINDS is in a very early stage of planning a major initiative on "Cognitive and Emotional Health."*

Proposed New Directions in Cognitive and Emotional Health of Children:

Goal 1: To assess the complex and multifaceted issues associated with disparities in cognitive & emotional health of minority children.

(a) Workshop on the Cognitive & Emotional Health of Minority Children. (Held July 23-24, 2001)

This workshop of national experts discussed the concept of "normal" cognitive and emotional development in children, and how to assess the defined "normality". This working group also focused on environmental and pharmacological effects as well as the result of neglect and other adverse conditions on the cognitive and emotional health of children resulting in recommendations on how to promote the normal development of all urban minority children.

The key activity associated with this goal is:

Workshop on the Cognitive & Emotional Health of Minority Children. (Held July 23-24, 2001)

Near-term performance measures are a prioritized listing of research areas, and development and release of PAs/RFAs targeted on the priority areas. Longer-term measures focus on number of high-quality applications for these target areas that are submitted and the number of these applications funded.

Goal 2: To improve current understanding of the interactions between chronic exposure to adverse environmental factors and the cognitive and emotional development of children.

(a) The NINDS will support studies assessing factors (prenatal, perinatal, environmental) influencing the cognitive and emotional development in minority children. The focus of these studies will be to characterize the relationship between health disparities, normal and dysfunctional cognitive development and functioning, including issues of prevalence, severity of

condition, risk factors, cognitive patterns that lead to life-long health problems in minority groups.

(b) The NINDS will support research on the long-term effects of "early experiences" (in utero, perinatal) on brain development and function. The goals of these studies will be to begin a community-based longitudinal study of minority children health and to develop collaborative partnerships with Federal agencies to join in the development and support of the study.

(c) The NINDS will encourage grantees to expand their ongoing cognitive neuroscience programs and explore new research projects that characterize the relationship between health disparities and the normal and dysfunctional cognitive and emotional development of minority children.

Key activities of this goal are:

- *Studies assessing factors (prenatal, perinatal, environmental) influencing the cognitive and emotional development in minority children. The focus of these studies will be to characterize the relationship between health disparities, normal and dysfunctional cognitive development and functioning, including issues of prevalence, severity of condition, risk factors, cognitive patterns that lead to life-long health problems in minority groups.*
- *Research on the long-term effects of "early experiences" (in utero, perinatal) on brain development and function. The goals of these studies will be to begin a community-based longitudinal study of minority children health and to develop collaborative partnerships with Federal agencies to join in the development and support of the study.*
- *Encourage grantees to expand their ongoing cognitive neuroscience programs and explore new research projects that characterize the relationship between health disparities and the normal and dysfunctional cognitive and emotional development of minority children.*

Near-term performance measures will focus on the establishment of the necessary structure to support the above lines of research: PAs/RFAs, collaborative partnerships, with longer-term measures focused on number of studies funded.

AREA OF FOCUS VI: Epilepsy and Status Epilepticus

Current Programs

The NINDS is supporting studies in the following areas:

- *Epilepsy Clinical Research Program*
- *Looking at Status Epilepticus in Minority Populations, a population-based study in Richmond, Virginia. It includes children.*
- *Public Education and Outreach Activities Related to Minority Health Disparities:*
- *NINDS Status Epilepticus Educational Program is a community education program in Richmond, Virginia, targeted in preventing prolonged seizures from developing into status epilepticus.*

- *Physician Education Program in Richmond, Virginia, is focused on early detection and treatment of status epilepticus, and it is intended for community physicians and emergency room staff.*

Proposed New Directions in Epilepsy and Status Epilepticus:

Goal 1: To establish the magnitude of the disparity in epilepsy and the nature of contributing factors.

(a) Planning Panel for National Workshop Minorities and Epilepsy.

A panel of experts will be convened to define research priorities and approaches for addressing epilepsy and status epilepticus in minority populations.

(b) Epilepsy in Minority Populations.

The NINDS will stimulate research focused on the frequency of epilepsy, its risk factors, clinical manifestations, natural history and prognosis in diverse minority populations. Research on specific populations will be encouraged, for example, in defined racial/ethnic communities or neighborhoods with representative minority populations (catchment areas).

(c) Secondary Epilepsy in Racial/Ethnic Minorities.

Research indicates that African Americans and Hispanics are at increased risk for stroke (especially at younger ages), while Native and African Americans are at higher risk for brain injury (due to accidents, firearms, low birth weight). Both conditions are known to be associated with epilepsy. The NINDS will support research on factors related to differential risk for secondary epilepsy, prognosis, and intractable seizures.

Primary activity of this goal is:

- *Planning Panel for National Workshop Minorities and Epilepsy.*

The key performance measure is a set of research priorities and approaches for addressing epilepsy and status epilepticus in minority populations. Among the targeted areas, NINDS anticipates there will be:

- *Epilepsy in Minority Populations.*
- *Secondary Epilepsy in Racial/Ethnic Minorities.*

Subsequent measures of performance will focus on number of submissions of high quality applications and number of such applications funded.

Goal 2: To establish the magnitude of the disparity in status epilepticus and the nature of contributing factors

(a) The Burden and Outcomes of Status Epilepticus.

Further research is needed to establish the frequency of, and the risk factors (e.g., access to care) for status epilepticus in African American, Hispanic, and Native American populations throughout the United States. The NINDS will stimulate research to further establish the magnitude and factors contributing to status epilepticus.

(b) Pathophysiology of Status Epilepticus in Minorities.

The NINDS will support studies to identify factors essential to the understanding of the basic mechanisms underlying this condition in minority populations. These factors include, but are not limited to cerebral vascular disease, genetics, sickle cell anemia, and alcoholism.

(c) Non-convulsive Status Epilepticus in Minority Populations.

Due to the high incidence of non-convulsive status epilepticus in coma and the frequency of coma itself, the overall incidence of status epilepticus may be much higher than previously anticipated. Given the potential genetic predisposition of this condition in African Americans and the preventable nature of the disorder, it is essential to evaluate its predisposing and precipitating factors, and to develop adequate strategies to address them.

This goal will be achieved through research directed at the following areas:

- *The Burden and Outcomes of Status Epilepticus.*
- *Pathophysiology of Status Epilepticus in Minorities.*
- *Non-convulsive Status Epilepticus in Minority Populations.*

Near-term performance measures for these activities include those indicating establishment of the necessary structure, for example, development and release of PAs/RFAs in the target areas. Longer-term measures include number of high-quality applications submitted on the targeted areas and number of those applications funded.

AREA OF FOCUS VII: Injury to the Developing Brain

Current Programs

The NINDS is supporting studies in the following areas:

- *Accidental and Non-accidental Pediatric Brain Injury*
- *Neuropsychological Outcomes of Neonatal Brain Injuries*
- *Randomized Indomethacin Intraventricular Hemorrhage Prevention Trial*
- *Beneficial Effects of Antenatal Magnesium (BEAM) is a six-year randomized trial testing the hypothesis that intravenous magnesium, given prophylactically to women who are about to deliver prematurely, will reduce the risk of infant mortality and moderate to severe cerebral palsy. This study is being conducted through the thirteen NICHD Maternal-Fetal Medicine Units Network around the country, representing a racially diverse population. Together, these*

centers are responsible for about 70,000 births per year.

Proposed New Directions in Injury to the Developing Brain:

Goal 1: To study the effects of biological and environmental factors in the immediate and long term outcomes of age-dependent brain injury.

(a) Injury and Outcomes to the Developing Brain Workshop.

The NINDS will convene national experts in the field of infant development and brain injury to identify key factors impacting on the frequency of perinatal, neonatal, and infant brain injury in order to plan a more comprehensive initiative to address those factors. The workshop will also identify potential factors affecting the outcome of sustained injuries to the developing brain, especially those amenable to prevention strategies. Special emphasis will be placed on permanent sequelae of repeated brain injury during the first few years of life. The recommendations from this workshop will assist the NINDS in setting research priorities and approaches to investigate potential interventions to improve the outcome of pediatric brain injuries in minority populations.

(b) Supplements to Existing Research on Developmental Brain Injury.

The NINDS will make available competitive supplements for additional analysis on existing data pertinent to injury of the developing brain from birth until late infancy. Also, supplements will be used to recruit additional minority participants to existing studies to increase the statistical power of on-going studies, and to make the results generalizable to minority populations.

For this goal, the primary activities are:

- *Injury and Outcomes to the Developing Brain Workshop.*
- *Supplements to Existing Research on Developmental Brain Injury.*

As previously noted for other goals involving workshops, the primary performance measure is a set of research priorities and the associated PAs/RFAs. Subsequent measures of performance will focus on the submission and funding of high-quality applications in the targeted areas.

AREA OF FOCUS VIII: Research Capacity Building and Enhanced Training among Minority Institutions and Researchers

Current Programs

The NINDS supports the following:

- *Developmental Neuroscience Research Program at the Morehouse School of Medicine is a*

Specialized Center Grant Cooperative Agreement Program co-supported by NCMHD as an Exploratory Neuroscience Research Center. The programmatic goals are to provide State-of-the-art infrastructure, to recruit neuroscientists, establish a Center of Excellence and effective research collaborations with leading extramural and Intramural laboratories.

- *Specialized Neuroscience Research Programs (SNRP) at Minority Institutions, jointly sponsored by the NINDS, NCRR, and ORMH, provide broad ranging support to augment and strengthen neuroscience programs while fostering collaborative research opportunities and promoting training and affiliations leading to the resolution of health needs in communities served by the SNRP awarded institutions.*
- *Society for Neuroscience Travel Fellowship increases the number of pre- and postdoctoral fellows from minority groups currently underrepresented in the neuroscience research. Participants are exposed to seminars and summer enrichment activities to facilitate their career advancement in neuroscience.*
- *Society for Advancement of Chicanos and Native Americans in Science (SACNAS) Neuroscience Scholarship Program aims to identify, recruit and develop minority pre- and postdoctoral students to engage in cutting-edge neuroscience research. Participants are exposed to seminars and summer enrichment activities to facilitate their career advancement in neuroscience.*
- *Collaborative Neurological Sciences Award provide for an investigator-initiated collaborative research project to develop independent neuroscience research programs at minority institutions.*
- *Ernest Everett Just Faculty Research Career Development Award provides for an intense period of supervised research for faculty at minority institutions.*
- *NIH Research Supplements for Underrepresented Minorities Program is part of an NIH initiative to increase the number of underrepresented minorities in biomedical research. The NINDS emphasizes the use of administrative supplements to attract and bolster research experiences and training activities for underrepresented minorities.*
- *Training Program for Physicians, allows minority physicians to receive clinical subspecialty training in clinical and basic research in the neurological sciences.*
- *Traineeships in Biotechnology Program support faculty and students from minority schools to participate in a course on Special Topics in Biotechnology (sponsored jointly with the Foundation for Advanced Education in the Sciences).*
- *NIH Scholarship Program for students selected for the NIH Undergraduate Scholarship Program for Individuals from Disadvantaged Background.*
- *National Hispanic, Native American, and African American Youth Initiatives in Health and Biomedical Research support workshops and laboratory tours for high school students.*
- *NINDS Mini-Sabbaticals Program allows minority scientists to work with NINDS investigators to enhance their scientific and research skills.*
- *Matching Supplements to Institutional National Research Service Awards support additional training slots on training grants if the program recruits and appoints a pre- or postdoctoral fellow from an underrepresented minority group.*

Other programs to include minority students/investigators:

- *Internships in Brain and Nervous System Research is a Summer program at the NINDS for*

academically talented high-school, undergraduate, graduate, and medical students.

- *Clinical Electives in Medical and Surgical Neurology provides rotations on the NIH campus for medical students contemplating a career in the neurological sciences.*
- *Clinical Research Training Program for Medical Students is a year-long tutorial program for medical students pursuing a career in health research.*
- *The NIH Academy, currently under development, is designed to create a diverse cadre of researchers to eliminate health disparities.*
- *Predoctoral and Postdoctoral Fellowships provide opportunities for students (predocs) and scientists to participate in clinical or basic laboratory research.*
- *Postbaccalaureate IRTA Fellowship Program provides a year of clinical and basic neuroscience research in the Institute's intramural research program.*
- *Howard Hughes-NIH Research Scholars Program for medical and dental students provides basic research training on the NIH campus.*
- *Meyerhoff Scholarship Program is an honor program for talented students in the areas of science, engineering, mathematics and computer science. The NINDS provides research training opportunities for Meyerhoff Scholars in its intramural laboratories.*

Proposed New Directions in Research Capacity Building and Enhanced Training Among Minority Institutions and Researchers:

Goal 1: Implementation of basic, translational and clinical neuroscience research programs at minority institutions to advance and promote our health disparities research agenda.

(a) Specialized Center Cooperative Agreements (U54).

The National Institute of Neurological Disorders and Stroke (NINDS), in collaboration with the National Center on Minority Health and Health Disparities (NCMHD), the National Center for Research Resources (NCRR), and the National Institute of Mental Health (NIMH), supports an innovative funding mechanism called Specialized Center Cooperative Agreement (U54) Programs. The purpose of these programs is to augment and strengthen the research capabilities of faculty, students, and fellows at minority institutions by supporting the development of new, or enhancement of ongoing, basic and clinical neuroscience research programs. The Specialized Center Cooperative Agreements strive to meet the following programmatic goals:

1. To assist in infrastructure development leading to well-established, state-of-the-art neuroscience research programs;
2. To foster innovative and effective partnerships and collaboration between minority institutions and established neuroscience laboratories at federal and non-federal research institutions;
3. To create, support and maintain a stimulating academic and intellectual milieu to inspire and prepare students and fellows to pursue research careers in neuroscience; and
4. To provide support to develop and sustain competitively funded neuroscience research projects and programs.

The NINDS currently supports 11 programs and 28 collaborating neuroscience research institutions. The NINDS seeks to establish a national collaborative network of research programs supported to conduct health disparities research.

(b) Stipend for Clinical Rotations.

The NINDS will include a stipend for up to ten medical students selected for clinical rotations at the NINDS. This support will encourage students from disadvantaged backgrounds to apply for these rotations.

(c) Establishment of Education Projects (R25) for Minority Neuroscience Scholars Programs in National Scientific Societies.

These programs are designed to enhance collaboration with scientific societies to identify and support the next generation of basic, clinical and translational neuroscientists; to stimulate communications between all segments of the research community interested in advancing neurologic health care; and to promote improved outreach to communities at increased risk for diseases and disorders of the nervous system. To achieve success in this initiative, the NINDS will partner with scientific societies to develop innovative programs to attract and retain minorities for future training and leadership positions in our extramural research community.

(d) The NINDS will continue its support for research training and research capacity building through expanded support for Collaborative Neurological Science Awards, National Research Service Awards (individual and institutional), Minority Research Supplements Awards, Matching Supplement Awards for Institutional National Research Service Awards, and Career Development Awards.

There are four activities associated with this goal:

- *Specialized Center Cooperative Agreements (U54).*
- *Stipend for Clinical Rotations.*
- *Establishment of Education Projects (R25) for Minority Neuroscience Scholars Programs in National Scientific Societies.*
- *Support for research training and research capacity building through expanded support for Collaborative Neurological Science Awards, National Research Service Awards (individual and institutional), Minority Research Supplements Awards, Matching Supplement Awards for Institutional National Research Service Awards, and Career Development Awards.*

For the first activity: Specialized Center Cooperative Agreements, near-term performance measures include submission and funding of an application for a program. Longer-term performance measures include establishment of the infrastructure for the program, establishment of the key collaborations with established external programs in stroke, submission and funding of high-quality applications for program-based research projects, and number of minority fellows or students involved in Center activities.

For the remaining activities, the key measure of performance emphasizes the level of participation. Thus, performance will be measured by number of stipends awarded; number of Scientific Societies with Minority Neuroscholars programs, number of education projects within programs or number of participants; and number of Collaborative Neurological Science Awards, National Research Service Awards, Minority Research Supplements Awards, etc.

AREA OF FOCUS IX: Dissemination of Public Information and Outreach

Current Programs

Public Education and Outreach Activities Related to Minority Health Disparities include several ongoing programs to disseminate educational information, and to assist in the treatment of stroke to minority populations.

- *Ambulance is a national 30-second televised public service announcement launched last year. This program is aired more frequently in the southern and southeastern states (Stroke Belt), where the frequency of stroke is unusually high.*
- *Healthbeat is a 60-second news and feature program on stroke that was aired on 900 stations to a total of 67,500,000 listeners. This program was especially targeting the Stroke Belt.*
- *Cuidando Su Salud in collaboration with the NINDS sent a stroke message to the Hispanic community. The show aired on 55 stations nationwide and in Puerto Rico, and was heard by about 15 million people.*
- *Health Fairs - the NINDS has supplied its stroke brochures to dozens of health fairs, many of them with underserved populations. Four brochures and a bookmark have been translated into Spanish.*
- *NINDS - Black Commissioned Officers Advisory Group partnership was formed to campaign for awareness and prevention of stroke.*

Proposed New Directions in Dissemination of Public Information and Outreach:

To increase dissemination of information about stroke, diabetes, and HIV to minority communities, the NINDS Office of Communications and Public Liaison will:

Goal 1: Expansion of Information Network

(a) Expand efforts to use the media, non-profit organizations, and professional societies for distribution of information about research, prevention, and treatment of these disorders.

(b) Expand listings of available resources for the public including relevant organizations. For example, to name the American Diabetes Association (ADA) on the Institute's diabetic neuropathy fact sheet since it offers a program targeted to African Americans.

This goal has two key activities:

- *Expand efforts to use the media, non-profit organizations, and professional societies for distribution of information about research, prevention, and treatment of these disorders.*
- *Expand listings of available resources for the public including relevant organizations.*

Measures of progress for this goal focus on level of activity, such as number of organizations that distribute information brochures regarding NINDS activities, number of organizations listed where resources may be found, etc.

Goal 2: Dissemination of Medical News/Information to the Public

(a) Partnerships with non-profit organizations to advance health messages of interest to minority communities and individuals at-risk for stroke, diabetes, and HIV-associated neurological complications.

(b) Improve the distribution of health information at meetings and events, including those where NINDS does not currently exhibit.

Key activities associated with this goal are:

- *Partnerships with non-profit organizations to advance health messages of interest to minority communities and individuals at-risk for stroke, diabetes, and HIV-associated neurological complications.*
- *Improve the distribution of health information at meetings and events, including those where NINDS does not currently exhibit.*

As with Goal 1, performance measures focus on level of activity, such as number of partnerships initiated and number of meetings where NINDS materials are distributed.

Goal 3: Development of New Communications Outlets

(a) Increase efforts to translate NINDS publications into Spanish, and provide links to Spanish-language publications and websites on the NINDS home page.

(b) Develop an email list service/interest group of individuals serving or representing minority communities and organizations to assist in efforts to reach their communities.

Activities associated with this goal are:

- *Increase efforts to translate NINDS publications into Spanish, and provide links to Spanish-language publications and websites on the NINDS home page.*
- *Develop an email list service/interest group of individuals serving or representing minority communities and organizations to assist in efforts to reach their communities.*

Measures of performance on this goal include number of NINDS publications translated into Spanish, establishment of links to Spanish-language publications and websites on the NINDS homepage, and establishment of an email list service. Longer-term performance measures will focus level of activity such as volume of use of the list service.

Goal 4: Disseminating the NINDS Health Disparities Strategic Plan (April-May 2000)

- (a) A draft of the plan was distributed via mail to individuals representing the minority biomedical and bio-behavioral communities and members of appropriate societies and organizations from which comments and suggestions were received and integrated into the plan.
- (b) The draft plan was posted on the NINDS home page and public comments and suggestions were encouraged.
- (c) A draft of the plan was issued to advocacy groups enlisting their support for and participation in specific projects outlined in the plan, and soliciting comments and suggestions.

This goal involves two activities:

- *Solicitation and integration of comments, suggestions and support for the draft of the Strategic Plan from individuals representing the minority biomedical and bio-behavioral communitiand members of appropriate societies and organization.*
- *Dissemination of final approved plan to these communities, societies and organizations.*

The first activity has been accomplished. The final plan is in development and will be made available to the nation via the NINDS website.

AREA OF FOCUS X: Inclusion Policies/Activities for Minorities in Clinical Research

Current Programs

The NINDS supports two clinical trials in stroke directed at specific ethnic populations.

- *African-American Antiplatelet Stroke Prevention Study is an on-going multicenter, randomized double-blind clinical trial of ticlopidine and aspirin in subjects with non-cardioembolic ischemic stroke. The study began in 1995, has 35 sites, and as of July, 1999, it has enrolled more than 1100 patients. The target is 1800 participants. Most patients in the study are overweight, and they suffer from hypertension, smoking, lack of exercise, and to a lesser extent diabetes, hypercholesteremia, and family history of stroke.*

- *Secondary Prevention in Small Subcortical Strokes is a pilot study in 100 patients at risk for lacunar infarcts. Lacunes comprise nearly 25% of brain infarcts, are harbingers of vascular dementia, and are particularly frequent in Mexican-Americans. Combination antiplatelet therapy and intensive lowering of blood pressure could substantially reduce major vascular events and cognitive decline in these patients. This is the first clinical trial to assess secondary prevention in lacunar infarcts, and specifically in Mexican-American subjects.*

Proposed New Directions in Inclusion Policies/Activities for Minorities in Clinical Research:

The NINDS proposes to establish a prevention/ intervention research networks throughout the extramural community. The goal is to foster stronger linkages between investigators at minority and majority institutions with community-based organizations to improve minority recruitment and retention in clinical studies.

Goal 1: Establish a National Network on Minority Health Disparities Prevention/Intervention Research in Neurological Disease.

(a) The NINDS proposes to establish a prevention/intervention research network throughout the extramural community.

The goal is to foster stronger linkages between investigators at minority and majority institutions with community-based organizations to improve minority recruitment and retention in clinical studies. The Specialized Center Grant Cooperative Agreement to support this network.

The key near-term performance measure is the number of extramural research organizations that are part of the network. Longer-term performance measures will focus on productivity of the network, such as number of minority professionals conducting this type of research within the network, number of submitted high-quality applications on minority health disparities issues, and similar measures.

PERFORMANCE AND OUTCOME MEASURES

The NINDS is proceeding with its health disparities planning activities to better define the research priorities and objectives for reducing the burden of neurological disease in minority populations. The proposed action plans and goals of our strategic plan are straightforward, measurable and will be implemented over the next several years.

The ultimate measure of performance or impact is the reduction or elimination of disparities in the burden of neurological disorders and stroke among the nation's population. Pragmatically, this long-term goal is achieved incrementally over time through development of the necessary research infrastructure and through the identification (that is, discovery) and subsequent implementation of replicable and sustainable interventions. These structures and processes are intermediate steps to achieving the primary outcome, namely, changes in health among populations with excessive disease burden, and provide the basis for measuring success toward the ultimate goal. Accordingly, the performance measures that the NINDS Minority Health Disparities programs will employ to assess progress emphasize indicators of structure and process.

TIMEFRAME FOR PLAN IMPLEMENTATION

The NINDS Five-Year Strategic Plan on Minority Health Disparities will unfold over Fiscal Years 2002_2006. Activities in Areas of Focus I (Stroke) and II (NeuroAIDS) have already begun. In Areas of Focus IV (Pain) and V (Cognitive and Emotional Health of Children), activities will be initiated within the next year. Activities in the other condition-specific Areas of Focus will be initiated in subsequent years of the plan. Activities associated with the general or cross-cutting Areas of Focus (Research Capacity, Dissemination, and Inclusion Policies/Activities) will be pursued in all years of the plan.

NINDS Health Disparities Budget
(Dollars in Millions)

Institute / Center	FY 2002			FY 2003		
	Research	Infrastructure	Outreach	Research	Infrastructure	Outreach
NINDS	\$27.60	\$7.20	\$1.70	\$30.50	\$7.20	\$1.70